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Crisis, Social Support, and the Family Response: Exploring the Narratives of Young Breast Cancer Survivors

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Abstract

This article explores how 70 younger women diagnosed with breast cancer draw on social support resources. We found that most respondents' core support networks were their families and social support came in several forms including emotional, tangible, and informational. However, we also found that many of our respondents relied on a distinct form of social support, *experiential support*, which has not been identified in current research. Experiential support is defined as a relationship with someone who has gone through a similar illness and can help provide first-hand information, insight, and even hope. We conclude that experiential support is an important area for future research on social support and health outcomes.

Keywords

breast cancer; social support; qualitative; family

Social support has long been recognized as an important component of physical and mental health. Countless positive health outcomes from improved weight loss (Kubota, Nagata, Sugiyama et al., 2008) to enhanced coping with drug addiction (Yan, Liu, Zeng et al., 2008) have been associated with having strong social support networks. For individuals with cancer, those who perceive high social support feel more positively adjusted to their diagnosis and treatment when compared to those with perceptions of low social support (Söllner, Zschocke, Zingg-Schir et al., 1999). In this article, we focus on one group of cancer patients who have been understudied in terms of their cancer experiences and utilization of social support – women diagnosed with breast cancer prior to forty years of age. It is important to specifically understand how younger women with breast cancer experience social support because of the positive benefits social support has on health outcomes. However, most work on cancer and social support has targeted other demographic groups such as older women with breast cancer. ***Our central objectives in this article are to (1) explore how younger women with breast cancer draw on social support by identifying their main social support networks, (2) examine the forms of social support they see as being the most important to their treatment and recovery experiences, and (3) suggest avenues for further research and enhanced social support services.*** We find that our respondents relied most heavily on family support networks and that they turned toward their families for many types of social support that have been identified by researchers including emotional, tangible, and informational support. We also find that our

respondents relied on and sought out a type of social support, both within and outside of their family networks, not identified in current research - *experiential support*. Our respondents' reliance on experiential support suggests that this type of support is an important avenue for further research and effective support services for those facing a serious health crisis – particularly those with an atypical diagnosis.

Current Perspectives on Social Support and Younger Women with Breast Cancer

Social Support and Cancer

Among those with breast cancer, social support has been found to be related to favorable health outcomes including reduced mortality and improved body image (Kroenke, Kubzansky, Schernhammer et al., 2006; Reynolds, Boyd, Blacklow et al., 1994, Uco, 2005) and even improved quality of life overall (Sammarco 2001). Moreover, researchers have identified several forms of social support - emotional, tangible, and informational – and have examined how these specific forms of support are able to provide benefits to individuals diagnosed with severe illnesses such as breast cancer (Bloom, Stewart, Johnston et al. 2001; Chantler, Podbilewicz-Schuller & Mortimer, 2005). *Emotional* support is support that makes the individual feel better, more secure, and/or better understood (Chantler, Podbilewicz-Schuller & Mortimer, 2005) and it centers on “expressions of empathy, love, trust, and caring” (Coreil, 2010: 110). Reynolds, Boyd, Blacklow et al. (1994) found that “the absence of close ties and perceived sources of emotional support were associated significantly with an increased breast cancer death rate” (253). *Tangible* (also referred to as instrumental) support “refers to specific resources that others may provide the individual, such as a loan of money, a ride to a medical community, or child care” (Bloom, Stewart, Johnston et al., 2001: 1514). Chantler, Podbilewicz-Schuller, and Mortimer (2005) found that tangible supports such as preparing a meal or assisting with housework provided a way for those going through breast cancer to feel more in control of their treatment and helped to reduce anxiety. *Informational* support refers to “the provision of knowledge relevant to the particular situation that individual is experiencing” (Bloom, Stewart, Johnston et al. 2001: 1514), such as a husband researching a particular treatment regimen online. Chantler, Podbilewicz-Schuller and Mortimer (2005) found that informational support from their physicians helped to relieve the stress of those going through breast cancer and assured these patients that their life was in “good hands.”

The above typology commonly referred to in current research on social support and health outcomes is not meant to be mutually exclusive or exhaustive, but other possible forms of social support are often not explored. Though we found evidence for all of the above types of social support as our respondents discussed their support systems, we find an important variant missing from current discussions of social support and its impact on health outcomes. We suggest that *experiential support* is another key form of social support that may help individuals cope with an illness. In brief, experiential support arises from a relationship with a person who has experienced a similar health trauma or crisis.

Younger Women with Breast Cancer and Social Support

While research has shown a link between social support and positive health outcomes, most research on breast cancer has not looked specifically at younger women with the disease. Although the likelihood of a woman developing breast cancer increases greatly with age, 7% of women with breast cancer are diagnosed before 40 years of age and breast cancer accounts for more than 40% of cancers in women under 40 (Anders, Johnson, Litton, Phillips et al. 2009). Despite the prevalence of breast cancer among younger women, younger women are often underrepresented in research on breast cancer in both clinical trials and psychosocial studies on issues such as social support (For discussion, see Fitch, Grey, Godel et al., 2008).

The research that has involved younger women finds that these patients face a different disease than older women because of the varying effects breast cancer has as a woman ages (de la Rochefordiere, 1993). For example, younger women often develop more aggressive forms of breast cancer, respond less well to treatment, and have higher rates of recurrence than their older counterparts (Anders & Hsu, 2008) and even have lower survival rates (Anders, Johnson, Litton, Phillips et al. 2009). In addition, younger women may also have different concerns in terms of survivorship and life after cancer such as how cancer will impact their careers and their ability to have children (Fitch, Grey, Godel et al., 2008; Peate, Meiser, Hickey & Friedlander, 2009). This group also reports more psychological distress post-diagnosis than older women (see Rohrer, 2009 for review). Hence, research on older women with breast cancer that finds beneficial social support systems (e.g., Kroenke, Kubzansky, Schernhammer et al., 2006) may not be completely applicable to the experiences of younger women. As a result, our article is intended to specifically understand how younger women utilize social support networks and what they perceived to be important social support resources.

Methods

Sample Recruitment

The primary data for this article comes from in-depth interviews with 70 women who were diagnosed with breast cancer prior to 40 years of age.ⁱ The women were solicited through recruitment advertisements distributed by healthcare, advocacy, charitable, and support group organizations aimed at those with breast cancer. Organizations that agreed to help recruit for this study typically sent a recruitment advertisement through an e-newsletter/email list or a recruitment advertisement was posted on a message/discussion board. Fliers were also posted in public spaces by several organizations where clients physically come in for treatment and support services.^{ii,iii}

Sample Characteristics

Table 1 presents an overview of our sample. At the time of their interviews, the mean age of respondents was 35.2 years and the average age of the respondents for their first breast cancer diagnosis was 32.9. 85.7% of respondents were diagnosed within the past 3 years with much of the sample still actively receiving treatments such as chemotherapy and radiation at the time of their interview. Additionally 58.6% of the women are currently married/partnered with an additional 8.6% are engaged to be married. Further, 40.0% of the respondents have children. Table 1 also shows that our sample is highly educated (81.4% have at least a Bachelor's degree) with most having professional or white-collar jobs. Finally, most of the women in our sample identify as either Caucasian (61.4%) or African-American (31.4%). Finally, all but two respondents have health insurance (2.9%).^{iv}

ⁱThe operationalization of “young” or “younger” varies greatly in research on women with breast cancer. Some studies have age ranges up to 50 or 51 years of age (Bloom, Stewart, Johnston et al. 2001; Sammarco, 2001). We chose the age range of 18–40 because this study is part of a larger research agenda on the impact of cancer on fertility and family goals and relationships (see footnote ii). Although some do become parents (either with biological children or through other means) after 40, most adults become first time parents by 40 (Child Trends, 2002); and between ages 18 and 40 is when most adults form long-term partnerships and/or marry (U.S. Census, 2005).

ⁱⁱThe sample is from a larger study that is looking at how younger women with breast cancer make treatment decisions with their physicians, their experiences during diagnosis and treatment, their experiences with secondary issues that arise from treatment such as potential infertility and the impact of a breast cancer diagnosis on their future and family/partnership plans. For the larger study, we have interviewed both patients and doctors and other healthcare workers who treat younger women with breast cancer. Here, we draw exclusively on the patient sample.

ⁱⁱⁱWe were initially concerned that the resulting sample would be much more politicized than younger women with breast cancer in general or would only include women who utilize support networks through advocacy organizations as their primary means of social and emotional support. However, we found that only a few women in our sample could be classified as highly involved in such networks or groups. Since being involved in the cyber community regarding breast cancer (such as joining an email list from an advocacy group or occasionally checking a message board) involves minimal, if any, commitment, we do not think the sample over represents those who are very immersed in the breast cancer community. Also, in some cases, the respondent had no involvement in the advocacy organization, but rather a friend or family member forwarded the recruitment advertisement onto them

Interview Procedures

Semi-structured phone interviews were conducted with respondents. Prior to the interview, respondents were read an IRB-approved statement of informed consent before they agreed to participate in the study. Interview topics included initial diagnosis experiences, family background, treatment concerns and decisions, and available support networks along with the impact of a diagnosis on future family plans and personal relationships. The interview schedule remained flexible – meaning that a respondent’s responses drove the interviewing process in order to accommodate their unique experiences and perspectives. Interviews averaged 60 minutes.

Analysis and Coding

We took a grounded theory approach to the data (Strauss & Corbin, 1998). Although we did find evidence of the various forms of social support that have been documented in other research on breast cancer (such as tangible support), we did not go into the data analysis with preconceived notions or seeking to document what forms of social support do or do not exist. Rather, we allowed the themes/forms of social support discussed below to emerge from the women’s own narratives.

We first examined who respondents felt were their primary support network by categorizing support providers into discrete categories including family members, friends, and more formalized venues like support groups. We then explored the types of social support that support networks provided. Initially, interviews were coded with very general open codes indicating instances of “social support.” We then developed more specific detailed, or axial codes, to identify the breadth and diversity of how social support was described (e.g., tangible support acts, experiential support relationships, formalized support groups). Hence, our discussion of types of social support reflect what younger women with breast cancer themselves identify as being important and memorable as they recount their experiences.

Our analytical approach with our qualitative data allowed us to reach “conceptual saturation” (Strauss & Corbin, 1998) and the themes we identify are representative of the consistency and similarities with which respondents discussed issues of social support and supportive relationships.

Findings – How Younger Women with Breast Cancer Draw on Social Support

Main Support Networks of Younger Women with Breast Cancer

To understand how young women draw on support resources during diagnosis, treatment, and early survivorship, we first established who these women turned to as their primary support networks. Most of our respondents considered their family as their main support network (over 91.4%) with the others describing friend networks as their main support system (most often due to the fact a respondent’s family was not physically close by). More formalized forms of social support, such as attending support groups, were utilized much less often among the younger women in our sample – and no respondents described support groups as being their central means of social support.^v Forty-four percent (44.3%) of our sample described attending

^{iv}While there is racial/ethnic diversity in our sample, in this article we focus on the commonality of experiences. We found only one point of difference in the utilization of social support across racial/ethnic groups. Those of racial/ethnic minority groups were somewhat more likely to discuss the role of faith and religious groups in their coping strategies. However, no one expressed religious groups as superseding their family support networks or experiential supportive relationships that we emphasize in this article.

^vIn almost all cases, respondents themselves defined a support group as being face-to-face interaction, organized, and often sponsored by a cancer or healthcare agency or a church – so the 44.3% refers to involvement in this type of activity. In a handful of cases, women also turned to the Internet and online breast cancer websites for social support, but most often these sites were used by respondents for information gathering regarding doctors, treatments and side effects and not as a mechanism of social support.

at least one support group session, with most describing their involvement as being only a single instance or occasional activity. In fact, 61.3% of respondents who mention going to a support group discuss feeling marginalized within support sessions because they see these groups, along with breast cancer organizations more generally, as targeting the needs of older breast cancer patients and survivors. For example, Allison, a 28-year-old married project associate with one child, feels isolated in her support group because most of the members are older with different concerns and experiences: ***“I recently have started going to support groups, probably about a month ago... I don’t really feel comfortable with them because they’re all 50 and 60 year-old women. They’re not exactly in my time. They don’t have children who are young, they’re not my age. They don’t have the same things. They’re treatment was different than mine was because they were diagnosed 10–15 years ago. Things like that. So I don’t lean on them as much as I would if they were my own age.”***

The main differences between themselves and older breast cancer survivors/patients that our respondents spoke of most often included treatment differences such having to undergo radiation/chemotherapy versus only having surgery, having small children at home to care for, dealing with potential infertility, and concerns over dating or establishing romantic relationships. The sentiments of our respondents mirror discussions within the breast cancer community regarding the lack of formalized social support services for this particular group this group (see Fitch, Grey, Godel et al., 2008 and Young Survival Coalition for discussion.)

Family as Emotional Support

Throughout respondent’s narratives, our respondents continually described how they turned to their families for emotional support. Emotional support is “the perceived availability of thoughtful, caring individuals to whom one can share one’s innermost thoughts and feelings” (Bloom, Stewart, Johnston, et al. 2001: 1516) and indicates that one is valued and loved (1514). This idea of emotional security was often the underlying definition of support for the respondents in our study. In fact, 95.7% percent of our sample recounted emotional support as being a key component of how their support networks provided social support. In their narratives, this idea of being emotionally cared for came through in two main ways: one, being able to talk to someone about their cancer and, two, having someone physically ***“being there.”***

Not surprisingly, being able talk to someone about concerns, fears, and even treatment options was very important and the most common way in which emotional support was described. For example, Donalyn, a 34-year-old customer service representative, described her husband as being the one person that she was able to talk to about everything that was going on, ***“Just my pains, my fears, would my cancer come back, would I ever get my period back.”*** For Rhonda, a 38-year old currently single scientist, talking with friends and family during her treatment and diagnosis was an important show of emotional support as she battled her disease: ***“I talked to my parents. I talked to my brother. I talked to a number of really close friends in California, via phone.... And I would talk to people about my fears and my concerns and my experience with everything. I mean I was pretty open about what I was going through.... It was really nice.”***

Caitlin, a 38-year old single underwriter, recalls talking to her ***“very supportive”*** parents and siblings about her fears and even ***“complaining”*** when she felt she could not go through another chemo session. In fact, she relied heavily on the almost daily phone calls from her family to get her through her treatment: ***“And then them sort of I guess long distance holding my hand with, [they’d say] “Well it’s bad but it’ll taper off and you only X many treatments to go” and “You’re almost done and you don’t have to do it again”. So they really kind of held my hands I guess you could say which really helped keep me going. Because I started out very focused, but once you’re getting in the middle of that you’re dealing with a whole lot of***

unpleasantness it gets a little harder to be so focused. They were very supportive in that manner.

Emotional support for our respondents was also found through family members (and less often friends) being physically present as well. By “***being there***” or physically present, family members provided emotional support as well. Having people around and physically close reinforced the sense that respondents were not going through their cancer alone and could rely on loved ones to see them through their treatments. Rhonda relied heavily on her conversations with family and friends to get her through her treatment. She also took great emotional comfort from her partner Selma’s physical presence. Rhonda believed that her partner of fourteen years, Selma, was fully committed to her as she went through chemotherapy because Selma came to all of her medical appointments: ***“To my partner, to my friends, to my family. I had a really big, strong, wonderful support group – support network that I turned to... My partner, at the time, came to all of my treatments and was there for all my doctor’s appointments and helped me through everything. That was a really great support.”***

Rhonda recalled this physical show of emotional support fondly throughout her interview despite the fact that she and her partner broke up after her treatment ended. Having family members physically close similarly gave Kari Anne a sense of emotional support. Kari Anne, a single 33-year-old marketing professional, turned to her parents when she needed to talk about her cancer and treatment, but Kari Anne’s siblings provided emotional support in a different way – by being physically present during her treatments, ***“My siblings, I think it was more just about the emotional support, something to hang out with ... It wasn’t really about talking about anything or more just like being together.”***

Family as Tangible Support

Respondents also frequently recalled instances of tangible support that were provided by their social support networks. Jasmine, a 33-year-old physician, discussed her fears about dying and infertility with her partner who provided much emotional support during. With her parents, she discussed more practical matters: ***“What issues did I discuss with my parents? My treatment options, where I would move to during my treatments. When I was initially diagnosed I was in this really dark, dank, moldy apartment and we didn’t think it was a good idea for me to stay there during the therapy. So we talked about where I should live. Things like that. I think a lot of the support that I got from them was during my surgery, during my chemotherapy when they were physically there just helping take care of me...”***

Many respondents like Jasmine relied heavily on shows of social support in the form of “tangible aid and service” (Coreil 2010; 110) that can help someone cope with an illness. In Jasmine’s case, her parents helped her devise a strategy so she could move to a new apartment that would be better for her during treatment and recovery. Within our sample, 71.4% of respondents discussed how such tangible shows of support were an important type of social support that helped them make it through this difficult experience – especially throughout their treatment which commonly involved surgery and chemotherapy. Tangible support included family members bringing over food while they were going through their treatment, giving financial advice, providing physical care during chemotherapy sessions, and driving the respondent to and from medical appointments. Also, since many in our sample have children (40%) and most have young children (under 10), many needed help with their children’s everyday needs and care. Respondents recalled how family members also often took care of their children as well – watching their children during their treatment, making meals for them, and so forth.

A crucial type of tangible support many women mentioned during their interviews was having family members being a “second set of ears” during medical appointments to make sure that

all of the information about diagnosis, treatment options, prognosis, and so forth would be remembered. For Carrie, a 40-year-old teacher, her mother and husband were supportive in part by being the ones who were essentially listening to all of the information from her healthcare team, ***“My husband went to every single appointment and my mother went to about half... I needed them there for support, to hear what the doctors were saying because, at first, I was so emotional, I’m not so sure I was even listening. So I needed them to at least be supportive and get the information that I might miss.”***

These practical acts of support were important to our respondents because they satisfied their practical needs in terms of care, but this type of support also further emphasized that they would not be going through their healthcare crisis alone. Allison, the 28-year-old married project manager discussed above, describes her marriage as becoming ***“stronger”*** because of her cancer. She describes how her husband’s practical, or tangible, shows of support emphasized his concern and his commitment to seeing her through her cancer: ***“I would just say that he was the biggest supporter that I could have ever expected. I mean he picked up the housework, he rubbed my feet when I felt like shit. I mean he was everything to me during everything. I mean he was so helpful, so caring, so, you know, he made me stronger seeing how much he helped me throughout.”***

Family as Informational Support

Informational support refers someone being able to provide needed facts and information (e.g., the contact information for an oncologist) and this form of support was also an important resource our respondents drew on in coping with their diagnosis and treatment. Almost all respondents described their healthcare teams as being their primary information and most were proactive in finding out additional information as well (through sources such as the internet or books). Informational support was also an important way that family members provided needed support – 40.0% of women in our sample discussed family members providing additional informational to them. Family members often looked up information on the Internet, looked into treatment options to help the respondent decide on a treatment plan, and Megan (discussed below) even consulted with her sister’s oncologist in another state.

A key type of informational support that respondents described was related to the “second set of ears” tangible support that many family members provided during doctor’s appointments. Often when family members provided this tangible assistance by documenting what was said, they also provided informational support by seeking out new information by becoming advocates for the respondent as well. Family members pressed physicians and other healthcare workers for additional information during appointments such as the availability of alternative treatment plans or the possible side effects of a given treatment. Many women in our study relied on their family members to find out additional information by proactively asking such questions. Donalyn needed her brother and husband to be good listeners, but also to take on active roles by asking questions of her healthcare team: ***“I know that my first visit with my surgical oncologist, my husband and my brother both went, and we were there for probably an hour and a half and they both came with a whole bunch of questions.”***

Megan, a 38-year-old unemployed teacher, had her husband with her for medical appointments in part because she was too emotionally upset to take in everything, but Megan also knew how important it was to have someone with her who could be ***“aggressive”*** because her sister and mother had both survived breast cancer. She saw first hand how important “pushy” family members could be in ensuring that someone get the best treatment available. Her husband was able to also to take on this aggressive role for her: ***“After working with my sister and her cancer, found that usually, for her, she was always really trying to please her doctors and stuff so needed a third party like me or my other sister, she was not married, to make sure that we’re asking all the questions and we’re kind of pushing. Because we found that she***

didn't really want to [ask questions] and it was easier to have another person. So, my husband kind of supported that role. So when there was a question I didn't want to ask, or I was afraid to ask, then he would go ahead and make sure it got asked and something would follow through, and he also took notes."

Experiential Support within and outside of Family Support Networks

Megan's experiences also bring up a unique way that respondents drew on social support resources. Megan's family also provided her with "*experiential support*" – the experience and insights of others who have gone through breast cancer themselves. In fact, 58.6% of respondents mentioned drawing on the experiences and knowledge of someone who had also faced breast cancer. A prime source of experiential support came through our respondents' own families. Though most cases of breast cancer do not have hereditary links, many families have faced a breast cancer diagnosis because women, in general, have a 1 in 8 risk of developing breast cancer in their lifetime (NCI, 2006). Thus, many of our respondents could draw on the experiences of female relatives who had gone through the disease.

Megan described herself as being "*really involved*" in her sister's cancer and knew in part what to expect when she was diagnosed herself. Ellen, a 26-year-old researcher, had been diagnosed with breast cancer at 23 and again at 25. At the time of her diagnosis, she considered her mother and sister to be her main support network. However, she feels she leaned more on her mother, because like herself, her mother was also diagnosed when she was a mother with young children: "*Well, my mom more than my sister because my mom is a breast cancer survivor... I would kind of bouncing ideas off of her head about whether do you really think it's safe if I don't do chemo. It was less, you know, more about asking her advice and kind of hearing myself talk and wanting to get her opinion on things ...*"

Kayla, a 30-year-old married housewife with two stepchildren, leaned on her grandmother more than other female relatives because her grandmother had survived breast cancer, "*My grandmother was actually diagnosed with it so her and I discussed what she went through emotionally and physically. And she I guess basically warned me or forewarned me what I would possibly go through*" Similarly, Amy, a 34-year-old married administrative assistant with one child, reached out to her mother and a cousin who were both breast cancer survivors in order to discuss issues like treatment options.

Marriane, a 35-year-old married mother of two and yoga instructor, was diagnosed with breast cancer when she was pregnant with her second child. Her experiences help to underscore the uniqueness of experiential support and its importance even when other forms of social support are present. Marianne described a rich support network with her husband as being the center of her support system providing her with much needed emotional support, "*My husband kind of does everything with me. He's my big support.*" Her husband also provided valuable informational support by looking at online sources for treatment options, which in her case were quite complicated because she was pregnant at the time of her diagnosis. She also had lots of tangible support from family and friends who helped out by caring for her toddler daughter because she was too weak after her chemo treatments, in part because she was pregnant at the time.

Marianne was also able to draw on experiential support from her mother, aunt, and grandmother who had all survived breast cancer themselves. Her mother and other female relatives did not just provide information on treatment, side effects, and so forth. Rather, they were able to provide personal insight into what it is like to have breast cancer and she relied on her mother to come to her medical appointments because she had been through the process herself. Her relatives also gave Marianne reassurance and examples of women who had beaten breast cancer. Experiential support is more than just someone providing information about a particular

illness, but rather it involves someone providing first-hand insight into the process and experience of having a particular illness as well providing hope and serving as an example of someone in a similar situation who was able to overcome the disease.

In our study, respondents in general described their families as very supportive – only occasionally did respondents voice concerns over having additional social support such as wanting a spouse to be more emotionally open or wanting someone to drive them to a chemotherapy session. It is notable then that experiential support was the only support type that respondents consistently wished they had more of and/or took steps to seek out outside of their family networks. Alisa, a 42-year-old married mother of two and an urban planner, felt that at times support from other survivors was more beneficial to her than talking to family members who have not gone through breast cancer, “*...I wasn't really willing to discuss everything with family because if someone hadn't gone through breast cancer it really was just me telling them a story about what I was going through and it was no use to me because I wasn't able to get any information or even real support. You know they'd be sorry and pity you, but that was not what I wanted.*”

Tamara, a 36-year-old married occupational therapist, describes her family as providing much needed emotional, tangible, and information support, but like Alisa, experiential support was still missing for her. Although her mother had experienced uterine cancer when Tamara was in college, Tamara did not see her mother's experience as one that could inform her on an experiential level because unlike her treatment for breast cancer that has been long and grueling, her mother only had a quick surgery. According to Tamara, “*I wouldn't necessarily consider it a true experience with cancer.*” For Tamara, experiential support could only come from someone whose experiences were closer to her own and she actively sought out experiential support outside of her family by seeking out others who had had breast cancer, or in Tamara's words, “*people who had [also] walked the path.*”

Since the effects of breast cancer can vary greatly by age, as described above, the availability of experiential support was not guaranteed (or sufficient) even when a family member was a breast cancer survivor. Respondents did not necessarily feel fully comforted by the experiences of mothers and aunts who were diagnosed with breast cancer much later in life. Even Marianne, who relied heavily on her mother, aunt, and grandmother as breast cancer survivors, needed a connection with someone who was also pregnant during her breast cancer battle - something her mother and other female relatives had not experienced. According to Marianne, “*I was really looking for like peer age group, and not even that, but just a young mother, I was really looking for that.*” Marianne expressed frustration at not being able to find more formalized support services for younger women more generally in her area. Eventually, she found a national network for pregnant women with cancer that was able to match her with a mentor who had been through a similar ordeal. According to Marianne, this type of experiential support gave her reassurance that she could make it through this healthcare crisis as well as her pregnancy: “*The Cancer and Pregnant¹ mentor was a big help to me because it was just nice to have somebody say, 'Yeah, I went through chemo when I was pregnant and my baby is fine.'*”

Similarly, Amy, discussed above, felt she needed additional experiential support outside of her family members who had histories of breast cancer. Though she turned to her mother and cousin for support and treatment information, they both were diagnosed at much older ages. She wishes she had tapped into organizations such as the Young Breast Cancer Patient Network² prior to beginning her chemotherapy regimen because of her concerns about fertility – a

¹All organizational names are pseudonyms.

²All organizational names are pseudonyms.

common source of concern women in our study, which they felt set them apart from older women with breast cancer. ***“[My concerns were] I would go through menopause and then stay that way at a very young age. Plus, I just wanted to be normal again. I didn’t want to have to deal with fertility issues because I didn’t have any problem conceiving my first child.”***

Unfortunately, 35.5% of our respondents described experiential support as being an unmet need at some point during their breast cancer experience. Some respondents, like Amy and Marianne, were able to go outside of their families to find much needed experiential support networks. Similarly, Alisa (discussed above) who had breast cancer twice, sought out more experientially supportive venues (including a support group and becoming involved in advocacy organizations) the second time around in order to get the experiential support she felt she could have used during her first diagnosis.

While many in our study including Amy, Marianne, and Alisa were successful in securing what they felt were beneficial experiential ties – not all the women in our study were so fortunate. Some of the respondents who desired greater, or any, experiential support were not always successful in finding it. For example, Catherine, a 27-year-old married chemical engineer, had a supportive family and was involved in a support group for those with breast cancer. However, her strong desire to have a child and being much younger than the other support group member limited the degree to which she could rely on her support group for experiential support: ***“My support group was a lot of older women and a lot of them weren’t going through the same thing. A lot of them children already and grandchildren even, and so there weren’t any young women in my support group. We mostly talked about the medical treatment aspect of it and side effects.... I didn’t really have a lot emotional connections in my group.”***

Marilyn, a 39-year-old single paralegal, describes having a supportive family network and many supportive friends at her church who had gone through breast cancer themselves. However, like Catherine, her experiential support needs were not entirely satisfied. Despite the support of several survivors (including her mother), Marilyn longed for a connection to someone she considers to be at a more similar life stage: ***“My support, as far as people who have gone through cancer and stuff like, was my church members. But they were older than me, old enough to be my mom or my grandmother so I didn’t have anyone my age who was going through the exact same thing that I was going through who was single. So I kind of wish that there was somebody else that was like that that I could have gotten in touch with to talk to and how they went through it and stuff like that because it’s difficult when you’re single and you’re going through this. I mean you’re thinking about what will a man say? How will he feel about that? And you know men are so physical.”***

Marilyn’s experience underscores how experiential support can be an unmet need for younger women going through breast cancer, but also how experiential support provides more than information on just treatments and side effects. Those who have been through breast cancer can help someone going through diagnosis and treatment how to deal with the overall impact that cancer has on someone’s life above and beyond their physical well being, such as dating relationships and future family plans. Marilyn’s experiences also point to the subjectivity in how people define what is “sufficient” experiential social support. For some, having someone in their life or family that had been through breast cancer was enough to fulfill their experiential needs (as in the case of Kayla), but others, like Marilyn, desired a connection with other breast cancer survivors who they saw as having more similar experiences to them in terms of age at diagnosis, treatment regimen, and/or life stage (i.e., single or being pregnant).

Conclusions and Future Research Directions

Our qualitative approach was also able to look in depth at the process of social support among women who were diagnosed with breast cancer prior to 40 years of age. By looking at the narrative accounts, we identify *what respondents themselves considered being important and memorable instances of social support*. By allowing breast cancer patients and survivors to define and discuss the types of support they saw as being vital to their recoveries, our findings broaden understandings of what younger women with breast cancer experience. For our sample, family member support resources were central to their narratives of how they experienced and coped with their diagnosis, treatment, and life after cancer. Moreover, many felt somewhat marginalized from more formalized support services (such as support groups) because of their age. Families provided the “most” emotional, tangible, and informational forms of social support along with many female relatives also providing much needed experiential support. But experiential support was not always found within family networks - even for those with a family history of breast cancer. It was only this type of social support that the women in our study actively sought outside of their families – sometimes successfully and sometimes not.

Our sample is limited in that it is homogenous in terms of socioeconomic status. Therefore we cannot assume that the social support processes we identify here would be similar for those who lack financial, occupational, and educational resources. Our respondents rarely, if ever, mentioned concerns over financial support, inadequate health care, or having adequate living conditions. It is possible that our respondents and their families were more able to focus on providing and receiving other modes of assistance such as emotional reassurance or enhanced experiential support because their basic life and health needs already being met.

However, the consistency of sentiments and experiences regarding social support among our middle-class sample raises questions for future research and advocacy efforts. Future research that seeks to statistically establish the relationship between social support and health outcomes could use the analysis provided here to develop detailed quantitative measurements of social support in its various forms. For example, survey scholars could measure emotional support by asking questions that tap into the two main dimensions of emotional support described by our respondents – one, having someone to talk to and, two, having someone physically close to provide another type of emotional comfort. Additionally, researchers could expand measures of informational support to include whether or not family members act as advocates on a patient’s behalf.

Most importantly, this study raises the potential value of *experiential support* for those facing a health crisis. Research on social support and health outcomes has tended to focus on only a few variants of social support – most typically emotional, tangible (or instrumental), and informational. We propose experiential support as a type of support not fully captured by these other forms. Experiential support is characterized by having ties to someone who has been through the same health crises under similar circumstances (such as being at a similar life stage or age) who can provide first-hand information, insights, and hope. For many of our respondents, experientially supportive relationships with a breast cancer survivor provided comfort and reassurance from someone who has also gone through something that outsiders may not fully be able to empathize with or ever completely understand.

Since family networks were the central support networks for the women in our study, instances of experiential support usually involved family members – sisters, aunts, and mothers who also had gone through breast cancer. There were also several examples of experiential support through more formalized support networks including support groups and advocacy organizations. Although many women in our study felt marginalized from more formalized

support services for those with breast cancer, those who described more fulfilling experiences were often involved with organizations that partnered them with another younger woman who had been through a similar diagnosis such as in the case of Jenel, a 35-year-old single teacher. She took great comfort in becoming involved in an organization that partners someone newly diagnosed with those who have been through a similar experience. According to Jenel, these mentoring relationships, “*took a little bit of the scare out of what was happening*” and helped to take “*that edge off of me*” as she progressed through her own treatment.

Researchers and those who work with individuals with serious illnesses more generally should explore the potential of experiential support, both within and outside of family networks, for positive health outcomes and improved quality of life post-treatment. Experiential support does not replace other forms of social support, but rather it is another form of social support that constitutes and augments an individual’s overall social support network as demonstrated by Marianne’s experiences. Future research should explore how experiential support can play into the experience of illness and recovery. Does having experiential support networks lead to improved health outcomes like lowered reoccurrence rates or improved quality of life post-cancer? Is experiential support more beneficial when someone is facing a rare disorder (e.g., a man facing breast cancer), a stigmatized health status (e.g., a person dealing with schizophrenia), or an atypical diagnosis (e.g., like a young woman having breast cancer)? How do those going through a serious illness decide that someone else does in fact “share” their experiences? Are support group services more effective when new members are partnered with those who have been through a similar health history? Experiential support networks were invaluable for many women in this study as they coped with having breast cancer and went through treatment and exploring this concept is important to more fully understand the breadth of valuable social support resources available to those facing a healthcare crisis.

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Table 1

Sample Characteristics

(n=70)	
<i>Race/Ethnicity</i>	
% Caucasian, Non-Hispanic	61.4%
% African-American	31.4%
% Caucasian, Hispanic	4.3%
% Asian	2.9%
<i>Educational Attainment</i>	
% with Bachelor's Degree or higher	81.4%
<i>Family Status</i>	
% Married/Partnered*	58.6%
% Engaged to be married	8.6%
% with Children**	40.0%
<i>Mean Age at time of interview (years)</i>	35.2
<i>Mean Age at time of first diagnosis (years)</i>	32.9
<i>Age Range at time of first diagnosis (years)</i>	23–39
<i>Less than 3 years since most recent diagnosis</i>	85.7%
<i>% with Health Insurance</i>	2.9%

* Partnered includes those women who are not legally married but consider themselves to be in permanent partnerships.

** This category indicates women who identify themselves as a parent. Although the overwhelming majority of women have biological children, this category also includes non-biological children including foster and stepchildren.